Enhanced Perinatal Surveillance Workshop

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Moderators—Mary Lou Lindegren and Teresa Hammett, Centers for Disease Control and Prevention (CDC)

Welcome and Opening Remarks—Patricia Fleming, CDC

Good morning! What we're talking about today is a really important challenge and a great opportunity for us. Surveillance data have a role to play and a contribution to make in terms of helping people find the best path for targeting prevention programs, monitoring what's really happening in the epidemic, and assessing the impact of prevention strategies and treatment programs. This project is really a test case of how well surveillance data can make a contribution in terms of evaluating the success of perinatal prevention programs.

There is a delicate balance between our primary role as a surveillance program and the role we play in providing data that can help other programs, such as prevention, assess how well they are doing. We have a lot of experience in evaluating the process of surveillance; for example, we evaluate whether we have complete case reporting? Are our data valid? Timely? Representative? For treatment intervention programs, and prevention services, where there is no long history of process evaluation, they are trying to develop effective and efficient ways of collecting data to evaluate the performance of their programs. Whereas we do not collect data about the process of such programs, apart from our own surveillance programs, we do hold the outcome data, through surveillance, that measure infection, disease and death, the conditions that our colleagues in prevention and treatment programs are trying to prevent.

Therefore, we have evaluation skills to offer: We actually do evaluate surveillance programs on an ongoing basis. We have a vested interest in our own process evaluation because we want to make our programs better. Prevention and treatment program staff are vested in evaluating their own programs. Because we have data that show the impact and outcomes of their prevention efforts, we need to be sensitive to prevention and treatment program needs for data to help them assess where they need to focus their efforts and identify underserved populations, as well as to demonstrate their successes. We need to recognize and balance the contribution we can make to their efforts and redefine the role of the surveillance-prevention partnership more collaboratively. Documenting the success of perinatal HIV prevention in collaboration with our prevention partners is an exciting surveillance opportunity because there are measurable, discrete events; we can envision how we can achieve our surveillance program objectives as well as prevention program objectives. If we can forge relationships with our partners on the prevention and treatment side of the perinatal arena, I think it will give us the tools that we need to go forward in the next 10 to 20 years. Perinatal HIV surveillance data define where we are doing a good job in

preventing transmission and where populations need more intensive programmatic interventions.

We have a lot of work to do and a lot of opportunities and challenges ahead. At the state and national levels, surveillance experts feel the same way. We have a lot of expertise in surveillance. We understand what our data mean and what they can do; we understand when we can collect additional data, whether it will be meaningful, useful, and relevant. We do not want to be silent partners in just answering data requests and passing out information. We want to be part of the planning, the thinking, the evaluation. We want to anticipate data needs from the program intervention side and to be there to guide whether it=s realistic, feasible, and meaningful for us to be able to collect data that would be helpful in assessing the impact of intervention programs on trends in the epidemic.

Introduction of States cMary Lou Lindegren, CDC

After giving all participants the opportunity to introduce themselves, Dr. Lindegren reminded everyone of Dr. Gayle=s challenge to attempt to eliminate perinatal HIV infection and how the states are helping the program accomplish its goals and helping them focus their efforts.

The day=s goals were as follows:

- To ensure everyone understands what Surveillance to Evaluate Prevention (STEP) is and how we=re going to implement it in a variety of different states, some of which are implementing HIV reporting and some not
- To establish what we=re going to get from our medical abstraction and what we should not expect to get
- To recognize what gaps need to be addressed by a different type of study

Goals and Objectives of Enhanced Perinatal Surveillance—

Teresa Hammett, CDC

The overall goals of prevention efforts are to maximize prevention of perinatal HIV infection with the ultimate goal of eliminating perinatal HIV transmission.

The overall goals of enhanced perinatal surveillance are

- To monitor the epidemic in women and perinatally exposed and infected children
- To monitor the impact of the PHS recommendations for counseling and testing of pregnant women and for zidovudine use prepartum, intrapartum, and in the neonate
- To assess resources needed in prevention and care
- To assist in timely evaluation of prevention efforts
- To evaluate the effects of in utero exposure to antiretroviral drugs

The specific objectives are

- To assess the use of prenatal care by HIV-positive women
- To determine the proportion of HIV-infected pregnant women giving birth each year, who are known to be infected before delivery; to determine the proportion of pregnant HIV-infected women who were offered, accepted, and received HIV testing; and to identify and characterize populations and health care settings where HIV testing is not timely
- To determine the proportion of pregnant HIV-infected women who were offered, accepted, and received antiretroviral drugs during the prenatal and intrapartum periods and whose children received antiretroviral drugs postnatally; and to identify and characterize populations and health care settings where maternal/neonatal antiretroviral drugs are less used
- To conduct follow-up of all HIV-exposed infants to determine their HIV status
- To estimate the effectiveness of antiretroviral drugs and evaluate changes in transmission rates due to receipt of these drugs
- To follow trends in effectiveness of interventions [e.g., elective cesarean deliveries, breast-feeding practices, treatment of concurrent sexually transmitted diseases (STDs)] in reducing perinatal HIV transmission
- To characterize missed opportunities for prevention of perinatal HIV transmission
- To determine what proportion of HIV-infected women and HIV-exposed children are receiving follow-up care according to Public Health Service (PHS) guidelines
- To assist in evaluation of prevention interventions for continued formulation and targeting of activities
- If state laws permit, to assess any short- or long-term adverse effects related to in utero exposure to ZDV and other antiretroviral drugs
- To evaluate, if possible, what proportion of children born to HIV-infected mothers have been identified by health care providers and reported through surveillance

The challenges are

- Communication of information is another barrier to this intervention (e.g., women may know their HIV status and may not communicate it to their labor and delivery or prenatal care

provider; therefore, this data may not be in the medical records). Suggestions include tear-off sheet, very detailed chart forms, and if the provider checks Ano,@ then why not?

- Characterizing missed opportunities is a two-pronged issue because we=re dealing with a mother and an infant.
- Offering of testing is not included on computerized medical records, but acceptance is.

Overview of STEP 1

CDC Perspective—Pascale Wortley
It=s great to see so many of you around the table. We started out with a handful of states**C**New Jersey, Louisiana, Michigan, and South Carolina**C**and then five additional states participated**C** Colorado, Indiana, Tennessee, Alabama, and Missouri. Now we=re blossoming into 26 states, which is really great.

It has become apparent that changes in the treatment of women as a result of the 076 protocol happened very quickly. But the bigger challenge is to increase testing, to give all women the opportunity to know their HIV status, and to get women into care. We have learned so much in the past that I anticipate this activity will move along very smoothly.

New Jersey—Diane Abatemarco
Refer to Workshop F, Evaluation of Prevention Programs

Louisiana—Karen Corson
Lessons Learned

Tracking System

- **$** An effective tracking system needs to be in place.
- **$** Using one system throughout the study is conducive to better record keeping.

Record Review

- **$** If a record is not found at first request, continue to request it. Records have shown up over a year after initial request.
- **$** Some hospitals have a delay in getting parts of the medical record to the Abig@ record.
- **$** Some hospitals have separate clinic records that must be requested separately.

Data Collection

Things that worked well

- **$** Counseling and testing
- **$** Pediatric AIDS Program (PAP)
- **$** Adolescent Spectrum of Disease (ASD)
- **$** Field epidemiologist updates
- **$** Birth match. We matched all women of childbearing age in the HIV/AIDS Reporting System (HARS) registry with Vital Statistics to ascertain whether they could have had infants in this time period (initial). Then we followed up with each of them. The matching index was from 10,000 (almost perfect) down to 0.1. We

got 60% to 70% of our cases from birth match. Confidentiality is an issue for both HIV/AIDS surveillance and Vital Statistics. It takes a long time (5B6 months) for surveillance personnel to use the Vital Statistics system. It is not recommended as a yearly procedure, but can be used to check completeness of reporting after the initial match.

- $ Laboratory surveillance. Has been extremely useful for ongoing case ascertainment.

Things That Did Not Work Well

- $ Interviews. May wait all day for one interview and have the person not show up.
- $ Abstraction form. Difficult to use.
- $ Six-month follow-up with children. Cannot follow up every child at 6 months because of the records review. We follow until they have seroreverted or have become positive, but not necessarily on that 6-, 12-month schedule.
- $ Diagstat vs. PEDS.

Michigan C

Holly Malamud, Linda Scott

Detroit

My first message is that a STEP coordinator and someone doing perinatal surveillance are one and the same. Although the abstraction form is different, your goals are the same. These data are in addition to HARS data and will be extremely beneficial.

Michigan has had HIV reporting since 1992. Our communicable disease laws include perinatal exposure as a reportable condition. Putting together mother-baby pairs is critical, and linking siblings is also very beneficial. We do not have laboratory reporting, so birth registry matching helped us with our reporting.

Ascertainment of mother-baby pairs

- $ HARS/birth registry match with Vital Records office to find unreported mothers
  - $ Looked for mothers aged 15-55, still alive.
  - $ 1993 through 1996, matched approximately 3 dozen new cases.
  - $ Every two years is sufficient.
- $ Benefits
  - $ New cases provide an opportunity to identify facilities that do not report.
  - $ Measures surveillance completeness of reporting.
- $ Difficulties with match
  - $ There are potential confidentiality conflicts with Vital Records.
  - $ There is a time lag.
- $ General comments
  - $ Opportunity to strengthen perinatal surveillance
  - $ Opportunity to connect with new facilities

- $ Opportunity to educate providers

Rural Michigan

- $ Interact with infection control professionals in the state.
  - $ Link case finding with increased reporting opportunities.
  - $ Publish periodic articles for their organizations, local newsletter.
  - $ Provide an educational program on surveillance/ prevention to members at one of their meetings.
- $ Communicate with nurse managers of obstetricians, gynecologists, pediatricians at community hospitals.
- $ Communicate with chairmen of community hospital Obstetrics, Gynecology, Pediatrics departments. They let you come and discuss perinatal surveillance activities and provide information to the group.
- $ Be alert to migrant health clinics in area of source of unreported women and children.
- $ In dealing with infections disease physicians
  - $ You may need to set up a system for periodic visits to assist with paperwork completion.
  - $ Be alert to the mother=s doctor managing the baby=s testing and medications separate from the baby=s pediatrician.
- $ Take advantage of immunization programs.
  - $ May have tracking programs that assist in following child both in immunization status and geographic location as children are often mobile.
  - $ Michigan Childhood Immunization Registry (MCIR) provides birth information electronically. All information is automatically downloaded two weeks after delivery and is accessible to any provider. It is also useful for finding children who were lost to follow-up. When immunized, these children will show up in this database, enabling you to identify the child=s provider.
- $ Local rural pediatricians
  - $ It is a time-consuming process to get into office. Be patient!
  - $ Do not call the pediatrician=s office on a Monday, when they are often overloaded with sick children. Calls when they are busiest make the office staff unhappy with your requests for information.
  - $ You often have to physically go to the office at their convenience to establish credentials and relationships for future phone status updates.
  - $ These visits are a great opportunity for educating staff and physicians.
- $ Rural local health department. When sending Aperinatally exposed@ case report forms to local health departments that may not routinely deal with HIV, include a letter explaining perinatal exposure. Provide a good explanation of what a perinatal exposure case report form is to avoid confusion and additional phone calls from local health department to the state.
- $ Bring good reference information to site visits.
  - $ Often questions are asked about treatment, guidelines, breast-feeding. These visits present great educational opportunities.
  - $ Often rural offices have limited access to information.

- $ Establishes improved relationship when information and follow-up is timely.

South Carolina—Donna Smith, Norma Harris

Donna Smith—South Carolina has an active surveillance system; we collect information on both HIV and AIDS cases. Looking at birth cohorts from 1993, 1995, 1996, and 1997, in 1993 we had about 12 children with pediatric AIDS or HIV. By 1996, 1997 we only had three children in each of those birth cohorts.

Missed opportunities

- $ The majority of cases are African American, which shows the health disparities in our state.
- $ During pregnancy—drug use, alcohol use, cigarette smoking
- $ Most HIV-infected children had mothers who had less than 10 prenatal care visits.
- $ Fourteen African American children and 2 white children did not receive all three arms of ZDV therapy. Five black children and two white children did receive all three arms.

Norma Harris—STEP data for PhD dissertation

Objectives

- $ To identify factors that were predictive of adequate prenatal care
- $ To identify factors that were predictive of having been prescribed all three arms of ZDV (prenatally, during labor and delivery, and neonatally to the infant).

Study design. This cohort study looked at 149 mother-child pairs in which the mothers were known to be infected prior to delivery in 1993, 1995, 1996, and 1997. Other variables examined were demographic, behavioral, treatment, and reproductive.

Findings

- $ Prenatal care. Mothers who had sexually transmitted diseases (STDs) were less likely to have gotten prenatal care.
- $ ZDV. Mothers who indicated drug use and mothers with STDs were less likely to have received all three arms of ZDV.

Study limitations. Small sample sizes

Study strengths

- $ Population based
- $ Comprehensive ZDV, not just prenatal ZDV

Conclusion. HIV-positive pregnant women in whom an STD is diagnosed during pregnancy are at an increased risk for transmitting HIV and other STDs to their unborn infants. Intervention strategies should include STD clinics and outreach activities to drug-using women. Efforts to increase access to and use of prenatal care to these women should be a priority.

Methods/Issues for Enhanced Perinatal Surveillance

BackgroundCMary Lou Lindegren

After the Pediatric AIDS Clinical Trials Group (PACTG) 076 results were published, surveillance responded on several levels. We adapted our case report forms to collect the information, and we started the STEP project. We began thinking how we could use enhanced methods. We explored birth registry matches and adapted that to our STEP 1 in 1996 and went back and collected data on 1993, 1995, 1996 cohorts. From that data, we learned a lot about usefulness of birth registry matches, which became part of routine surveillance activities. STEP also had an enhanced supplemental data collection form, which we=re going to review.

So our lessons learned were twofold. We learned 1) enhanced methods from STEP, which we have now applied to routine surveillance, and 2) enhanced data collection from multiple sources. The quality of the data was such that the Institute of Medicine (IOM) used the data as the basis for their recommendations and was also part of the way we got additional funding for this initiative.

So for those of you who were not involved, your predecessors in STEP 1 paved the way for you to have this opportunity to collect these supplemental data.

Overview of Draft Protocol—Teresa Hammett

Timeframe

Those of you who were involved with the STEP project already have data from 1993 through either 1996, 1997, or 1998. For those who are just beginning data collection for enhanced perinatal surveillance, we must decide what year(s) to use as baseline data. Does anyone want to use years before 1998 as baseline? Ideally, we want to collect data from 1999 and 2000, and prospectively thereafter.

Population

Ideally, we would like to have information on all HIV-exposed children and their HIV-positive mothers. CDC must receive documentation of the state=s authority to access these records in those non–HIV-infection reporting areas or possibly in HIV-infection reporting areas if there is an issue of collecting data on exposed children. Review your state HIV reporting regulations to be sure you can legitimately access these records. Some states may need to get Institutional Review Board (IRB) approval to collect the data.

Study Design

- Ascertainment of HIV-positive mothers and exposed infants
  - Active case findings at pediatric sites and obstetric hospitals
  - Laboratory reporting
  - Women pregnant at time of report
  - Matching of HIV/AIDS registries and birth registries
  - Additional data sources (e.g., immunization registry, STD records)

Methods

- Methods for states without named HIV surveillance
  - May need IRB approval at specific facilities.
  - Criteria for selection of facilities vary, mostly go by numbers of infected babies born at a particular site.
  - Need mechanisms to link mother=s and child=s records.
  - Need to explore methods of reporting data to CDC. (e.g., Soundex with date of birth)
  - Monitoring data on perinatal AIDS reporting. Identify missed opportunities, reasons why these children became infected and progressed to AIDS. Complete entire case report and supplemental data form.
- Abstracting existing medical records
  - Records to be abstracted include HIV/AIDS case report, mother=s HIV clinic prenatal, labor and delivery, newborn hospital, pediatric HIV clinic, birth certificate records.
  - Data to be collected include basic demographic information of mother and child.
    - Mother=s information includes prenatal care, testing history, prenatal antiretroviral therapy (ART), drug use, sexually transmitted disease (STD) history, other HIV prevention interventions, access to postpartum care, delivery information.
    - Child=s information includes ART, mother=s HIV status, birth defects and follow-up information (access to care, receipt of prophylaxis and treatment, breast-feeding, adverse outcome related to in utero exposure to ART).
- Follow-up abstraction from child=s records every 6 months
  - Follow-up every 6 months until documented as a seroreverter or until AIDS and death.
  - Determine if the child was breast-fed.
  - Monitor HIV treatment and care for HIV-positive mother and child, if infected.
  - Assess potential adverse outcomes of in utero exposure to ART.
- Methods
  - Data management
    - Security and confidentiality. CDC Security and Confidentiality Guidelines are available.
    - Multiple ways of identifying women. Tracking methods in Michigan, Louisiana, and South Carolina have been discussed.
    - How data transferred to CDC
  - Data evaluations
    - Completeness of mother-infant pairs
    - Completeness and validity of data for match
    - In non-named HIV reporting states, need to evaluate the identifier used.
  - Quality assurance. Reabstract 5% of records.

Issues to Discuss

- $ Importance of reporting all HIV-exposed infants
- $ What years to use as baseline
- $ Timing of chart review, to minimize need to re-review
- $ What to do if birth occurs in one state and care in another
- $ How to collect data on mother-infant pairs located outside of IRB-approved site
- $ Common methods of reporting HIV-positive mothers and exposed infants to CDC
- $ Timeliness
- $ Evaluation of surveillance program performance

Overview of Draft Data Collection Form—Mary Lou Lindegren

Types of Data. Changes to Standard Case Report Form and Enhanced Data Form were discussed in page-by-page detail.

Medicaid and Managed Care—Kathy Rauch, CDC

Why is Medicaid important to perinatal HIV surveillance?
Medicaid is the largest source of HIV/AIDS financing in the United States. Medicaid's estimated $3.9 billion of HIV/AIDS related expenditures are more than twice the $1.4 billion that was spent under the Ryan White CARE Act in 1999. According to the Health Care Financing Administration (HCFA), Medicaid serves over 50% of persons living with AIDS and up to 90% of all children with AIDS.

Recent state and national legislation is likely to expand eligibility to include other low-income HIV-positive persons as well.

In 1998, Medicaid insured 30.9 million people, predominantly poor children and their parents.

From the National Survey of Family Growth, of women aged 15 to 44 who delivered a live infant in 1991-1995, Medicaid covered 56% of births to Hispanic women, 23% to non-Hispanic women, and 62% to non-Hispanic black women.

Some states have matched their registries against Medicaid claims to enhance case-finding or to gather other information and have obtained the data using the HCFA/HRSA/CDC model data-sharing agreement. This includes at least MD, NYS, DE, and FL. If you need technical assistance on matching, call Lisa Lee or Kim Marsh at 404.639.2052.

MA plans to review its Medicaid claims database and create and analyze a sample to determine changes over time in the rate of HIV antibody testing among pregnant women and also the rate of provision of antiretroviral therapy. This is a good mechanism to evaluate perinatal prevention efforts.

Why is Medicaid managed care important to surveillance?
Medicaid beneficiaries receive care from managed care organizations or from independent physicians on a fee-for-service basis. In 1998, 16.6 million (54%) of beneficiaries were enrolled in some form of managed care. Medicaid enrollment rates by state are available at www.HCFA.gov.

How can states influence reporting from managed care?
The IOM recommended that health care purchasers such as Medicaid agencies adopt contract language supporting a policy of universal HIV testing.

Last fall, George Washington University, in collaboration with CDC and HRSA, finalized a document called ASample Managed Care Purchasing Specifications for the Prevention and Medical Management of HIV/AIDS.@ This contract language is primarily intended for Medicaid agencies to use in their contracts with managed care organizations. It contains, for example, HIV benefits and services that should be provided as well as sample reporting requirements. Use of the language is optional.

The IOM also recommended that health care plans and providers adopt performance measures supporting a policy of universal HIV testing. CDC has a contract with the Foundation for Accountability, a performance measurement developer, to develop and field test the measure Aproportion of pregnant enrollees who were tested for HIV during pregnancy.@ As soon as this measure is successfully field tested, hopefully this summer, it will be distributed to public health, Medicaid, and other agencies. If this measure were adopted by Medicaid agencies and public health were able to obtain the data, it would enable you to evaluate perinatal HIV prevention efforts at least in those plans that report their data.

Yesterday, Brian Gallagher told me that when NYS matches birth certificates to the HIV registry and find positives reported from managed care organizations, they report back to the managed care organization on prenatal care issues. This appears to be a good use of the matching process to enhance perinatal HIV prevention in health care organizations that have relatively little experience with disadvantaged populations.

Public health officials should encourage state Medicaid agencies to
- **$** make perinatal HIV prevention a priority.
- **$** ensure that HIV prevention and care services are in the capitation rate or paid through direct billing.
- **$** include specific language on HIV benefits and services in Requests for Proposal (RFPs), managed care contracts, and Primary Care Case Manager (PCCM) letters or contracts.

Public health officials should advise Medicaid providers of HIV prevention policies and available resources.

Access to Maternal and Perinatally Exposed Infants= Records

1. HIV Reporting StateCNJ, John Biel, Diane Abatemarco
In New Jersey, we are trying to come up with a hybrid of STEP and Enhanced Perinatal Surveillance. We linked raw STEP data to HARS and linked both databases to the birth registry. Things like marital status and education levels are helpful.

We=ll be using the STEP data to provide a profile for those involved with prevention. We will sit on the perinatal prevention task forces (state and 3 local, municipal) and will give Supplement to HIV/AIDS Surveillance (SHAS) data as a profile. So we=ll be giving data from HARS, Survey of Childbearing Women (SCBW) to those involved with prevention efforts.

We=ve helped to change the birth registry by adding an additional module about HIV counseling for mothers who have delivered a live infant. It has to do with counseling, specimen obtaining, and source of the HIV information. A copy of the module is available.

Lessons Learned from STEP
- **$** A large number of women received inadequate or no prenatal care.
- **$** There is an association between whether women get AZT in prenatal care and whether they received provider counseling.
- **$** The few (5%) who refused testing often had been tested prior and knew their status.
- **$** 71% of women received intravenous zidovudine during pregnancy, > 85% if both intravenous and oral administration are included.
- **$** We need more training to avoid inconsistencies. For example, Ano prenatal care@ may be marked Ayes,@ but then prenatal care visits are indicated later. We have considered having a public health resident talk about medical records from a physician=s point of view.

Next STEP will work with prevention to provide them with technical assistance and data. We will examine
- **$** Adverse events from combination therapy
- **$** Resistance to therapy
- **$** Perinatal exposure
- **$** Viral load. NJ=s law will change in June 2000 to include reporting of viral load.
- **$** Mode of delivery (elective cesarean delivery for HIV prevention)

Birth Registry Match
We=ve been linking mothers and infants since August 1994, so we have about 6 years of experience. The first birth registry match was from 1993, when we had 120,000 births. We eliminated from HARS women who were too young or too old to have had babies, very young women (girls) who were having babies, women who were dead, and women for whom we already had pairs (237). On the birth certificates we have the mother=s maiden name, an informant=s name,

and the father=s name. We decided to use the mother=s first name, date of birth, and matched 651. Of these, we matched 174.

2. AIDS Reporting StateCNYC, Pauline Thomas, Annette Brooks
We were funded in 1989 to do the Pediatric Spectrum of Disease (PSD) project, which was implemented at 10 sites and saw about 50% of our pediatric AIDS cases. Those 10 sites continue to cover about 1/3 of the HIV-infected children in NYC. In 1991, we received supplemental funding for more pediatric HIV surveillance. With that funding, we started doing just HARS-based data collection at an additional 12 sites. All our data are initially collected on HARS forms. PSD has additional data collected on a 6-month basis. We review all newborn and pediatric charts (only) of HIV-infected and -exposed children in care of the 22 hospitals. We do not look at the mothers= charts. We re-review the charts about every 6 months.

We are not permitted to bring names into the office, but this is going to change in perhaps April when we have HIV surveillance implemented in NYS. We have hard copy and/or computerized names logs at the sites under the auspices of the pediatrician. We bring in the data without identifiers. We complete the HARS form at the site and do put the Soundex and date of birth on the HARS form. That=s what gets brought into the office and entered into the database.

We run duplicate checks and matches with AIDS cases. AIDS cases are matched every quarter to the bioregistry data, mainly death certificates. Birth registry matches we do irregularly, and we produce a semiannual report, the pink report I=ve passed around.

Without names, we have been able to pick up in surveillance approximately two-thirds of all the HIV-infected children in NYC in the past two years. Before that, it was less than two-thirds because all the children were not being identified.

We are able to look at prevention efforts, all births to women who received prenatal care at one of our sites. We have the percent of women who got at least ZDV and the percent who received ZDV plus something else. That=s not a local field. That=s using Mary Lou=s codes. That information is a write-in on AWhat other drugs are received?@

How do we do this? You need a simple written protocol. Two weeks after sending a letter to the site, we would call and ask when we can meet them. This worked in 22 of 23 hospitals that agreed to participate. We got IRB approval from the health department under the mandate of monitoring an epidemic. No site has felt the need to continue annual IRB approvals.

It=s very important to maintain contact with your site. Continuing contact with pediatricians helps them feel better about your staff members coming in and abstracting charts. We send them copies of papers for comment; we share CDC publications and provide a report of how their hospital looks compared with the rest of the city. It=s a way of encouraging reporting that goes beyond AIDS.

3. UI Reporting StateCIllinois (Chicago), Jim Murphy, Margarita Reina, Yolanda Olszewski
Background. HIV reporting by non-named coded identifier began in Chicago on July 1, 1999. Response and compliance has been that we can=t get cases entered faster than they come in. Because Vital Records is part of the same program, we have easy access to both birth and death registries. Also, we work with SAS programmers who have assisted us in doing the matches with HARS and the death registry.

Seroprevalence SCBW in IL was continued after 1995, funded by the state, so we have 1996 and 1997 data. Most recently, our seroprevalence rate was 0.28 and has remained consistent in the >90s. Of 50,000 births per year in the city of Chicago, we estimate 125 births per year to HIV-positive women.

Another advantage is because this has been determined by CDC to be routine surveillance and not a research project, the municipal codes of the city of Chicago state that the health department has access to any medical record held for purposes of surveillance. So although we cannot walk out the door with the names, we can review the medical records.

Plan. We=ve already heard a lot about matching with birth registries and HARS data; the only thing new is the patient code numbers. We=re going to create a patient code number for the mothers that will match the birth registries; but the name of the birth mother will be her maiden name, so we=re going to generate at least two possible patient code numbers and match that with the birth registry of the maiden name and name of the baby. So we will match that with the HARS data of the women, and through the birth certificate we will find out the birthing hospital and then pull the birth certificate and locate the birth record and the prenatal record and the provider. These records will be abstracted.

We plan to go through it two ways: the women from the HARS data and through the pediatric cases we have. Of course we have the name reporting for the AIDS cases, and we just got started on HIV reporting. So we=ll have the Patient Code Number (PCN) for the HIV pediatric cases and the names from the AIDS cases. And we=ll do the same thing with the birth registries, generating the same possible PCNs. PCNs are generated by using a few letters in the last name, the number of letters in the last name, gender, and date of birth.

Other sources are the 16 major birthing hospitals that reported at least one birth to an HIV-positive mother, five perinatal networks in Chicago, and pediatric specialties HIV/AIDS clinics, and registry matches. We=re also going to review discharge summaries and continue to provide training.

Using Data to Enhance Maximal Reduction of Perinatal Prevention

ResourcesC Larry Edmonds, CDC (lde2@cdc.gov)
C The January 2000 issue of *Teratology* is a good resource; it describes what every state does in

birth defect surveillance.

- We have seven centers for birth defects research around the country. We allow them to do local investigator-initiated research. Two (NY and NJ) have chosen HIV and perinatal drug exposures. They will follow up and see the outcomes and drug exposure. So these will be a good source.
- About 40 states have a program or are trying to set one up. The National Birth Defect Prevention Network has a website, which also links you to state birth defects websites.

Development of a Perinatal Epi Profile — A.D. McNaghten, CDC

What is an Epi Profile?

It is information from a variety of sources summarized into one document to characterize persons infected and persons at risk for infection. It helps HIV prevention planning groups make decisions about prevention and interventions. Many of you have produced data for an epi profile, or you've actually produced part or all of an epi profile.

Uses of an Epi Profile

To provide an understanding of the HIV epidemic among populations in the planning region

- Magnitude (number of cases)
- Impact (rates)
- Distribution

To characterize populations at risk for HIV infection

To provide scientific data and foundation for the planning process and the subsequent steps

Four Key Questions

1. What are the sociodemographics of the population? (This describes the characteristics of your project area, so you can better plan prevention amd interventions. A perinatal profile might focus on women of childbearing age, women who have given birth, and children.)
    - Population size
    - Proportion of the population represented
    - Racial/ethnic composition
    - Socioeconomics (e.g., unemployment, poverty)
2. What is the impact of HIV/AIDS? (This is surveillance data to assess extent of existing epidemic)
    - HIV and AIDS cases (newly diagnosed perinatally infected HIV cases, incidence of perinatal AIDS cases, and trends over time)
    - How the mother was exposed to HIV
    - HIV-related deaths among perinatal cases (increasing or decreasing?)
3. Who is at risk for becoming infected? (This describes information on behaviors that increase the risk of perinatal transmission of HIV.)
    - What is the number of HIV-infected women giving birth (who do or not know their HIV status)?
    - Identify areas of high prevalence, particularly among women of childbearing age.

- Are women being offered HIV counseling and testing?
- Are HIV-infected women being offered ZDV or other ART for themselves or their newborns?
- Are providers screening pregnant women for STDs, group B Strep, hepatitis C?

4. What is the geographic distribution of infection? (This identifies where prevention and interventions are needed.)
    - HIV and risk information are unevenly distributed geographically within jurisdictions.
    - The concentration of HIV/AIDS cases or high-risk behavior should be defined geographically.
    - Identifying areas with a high concentration of HIV infection or high-risk behavior may indicate where prevention/intervention is most urgently needed.

Data Sources (Not everyone will have the same data sources.)

- AIDS surveillance
- HIV surveillance
- Survey of Childbearing Women (SCBW)
- Supplement to HIV/AIDS Surveillance (SHAS)
- Pregnancy Risk Assessment Monitoring system (PRAMS)
- STEP
- Enhanced Surveillance for Perinatal Prevention
- Pediatric Spectrum of Disease (PSD)
- Mother Infant Rapid Intervention at Delivery (MIRIAD)
- STDs, Group B Strep, hepatitis C
- Vital Statistics (birth and death certificates)
- Census

Benefits of a Perinatal Epi Profile

Summarizes data from a variety of sources.

$ All relevant data sources in one document.
$ May prevent the collection of duplicate data.
$ Can be used for prevention and care.

Pediatric Spectrum of Disease (PSD)—Andrew Fullem, MA

Massachusetts, like Illinois, has recently adopted the unique identifier (UI) HIV surveillance (January 1999), but for years has been part of a project called Pediatric Spectrum of Disease. It has functioned as a statewide surveillance system for pediatric HIV infection.

Background of PSD

- PSD is funded by CDC to the University of Massachusetts, not the Department of Public Health.
- HIV surveillance began in Massachusetts on January 1, 1999.

- It uses non-name identifiers.
- It measures both incident and prevalent infection.
- Participation is required by all licensed providers and facilities in the state.
- It covers all Massachusetts residents.

Pediatric Spectrum of Disease

$ Is it a statewide program.

$ It involves seven health care facilities (These facilities see 95% of all HIV-positive pregnant women in MA. A nurse abstractor is employed on site at each facility.)

$ Additional local specific (maternal) information is collected.

PSD Data on Perinatal Infection

$ 1350 children were born to HIV-infected women.

$ 89% (1202) are still alive.

$ 71% (940) are members of a community of color.

$ Nearly 60% (791) of infections are due to injection drug use (mother or mother's sexual partner).

$ 30% (491) children are infected.

$ There have been fewer than five children infected in each of the past two years.

Prenatal Care Characteristics (of 101 women who delivered between 1995 and 1998)

$ When did women find out they were HIV-infected?
- Before pregnancy (57%)
- During pregnancy (34%)
- After pregnancy or never (9%)

$ When did they enter prenatal care?
- Before 14 weeks (63%)
- Between 14 and 19 weeks (23%)
- After 20 or more weeks (8%)

HIV Status (34 women , 1995–1998)

$ Women who did not know their HIV status prior to delivery
- 68% of women were from a community of color.
- 41% were born in Puerto Rico or outside the United States.
- 85% had received some prenatal care.

$ Why did they not know?
- Previously tested negative.
- Did not perceive themselves at risk.
- Refused testing.

Prenatal AZT

Of 82 pregnant women in 1998, 76 received prenatal AZT.

Prenatal Care Record Review (317 records reviewed at 3 hospitals)

- $ 39% had documentation of HIV testing.
- $ Documentation varied by site and by insurance. (61% of those seen at a hospital-based clinic or HMO had documentation of HIV testing, compared with only 29% of women seen in private provider's offices.)
- $ Focus groups showed
  - Providers are hesitant to record HIV testing information.
  - Community health centers refer women out for counseling and testing.

The Future
- $ Collaboration between HIV/AIDS Surveillance and PSD. Enhanced surveillance is an opportunity to augment what is already working well as a statewide system.
- $ Registry. We are trying to address the issue of long-term registry early, to get community backing.
- $ Evaluation of prevention efforts. HIV/AIDS Bureau has invited both surveillance and PSD to be members of their evaluation group as well as planning prevention programs.

Pregnancy Risk Assessment Monitoring System (PRAMS) —Mary Lyn Gaffield, CDC

What is PRAMS?

PRAMS is an ongoing population-based surveillance system that collects information on maternal behaviors and experiences before, during, and after delivery (live births). Although initiated in 1987 for other reasons, only since 1996 has HIV-related information been collected. Mothers are selected using stratified, systematic sampling of state resident birth certificates. From 150 to 300 women from each state each month are sampled. Questionnaires are mailed, followed by a telephone call. Data are analyzed from states that achieve at least a 70% response rate to the entire questionnaire.

What are the selection criteria?
- $ Mothers who are mentally incompetent, have died, or who have adopted their child are not included.
- $ Babies who have died after birth, who do have a birth certificate, are included.
- $ Multiple births that are twins or triplets included, but multiple births involving four or more siblings are excluded.

Which states are currently participating?
- $ WA, AK, OK, AL, FL, SC, NY State, ME, WV have weighted 1996, 1997, and 1998 data.
- $ GA has weighted data for 1996 and 1997.
- $ CO, AR, NC have weighted data for 1997 and 1998.
- $ IL, LA, NM have weighted data for 1998.
- $ UT, NE, HI, OH, MD, NYC, VT will have weighted data beginning with 1999 or 2000 births.

Trends in HIV Test Counseling

- **$** In 1996, 69.7%; 1997, 73.3%; 1998, 77.6%
- **$** Significant increases in private sector counseling (4 states)
- **$** Significant increases among public sector providers
- **$** Significant increases among women who entered prenatal care early (4 states)
  - No differences for black or Hispanic women
  - Improvement for white women (4 states)

Trends in Prevention Counseling. Remained flat.

Trends in Testing

- **$** FL testing has leveled off, but the increase remains statistically significant.
- **$** OK testing increased.
- **$** Minimal difference but high levels of testing among women whose provider talked to them about counseling

Limitations

- **$** Data are not qualitative (context in which counseling was provided).
- **$** Prior history of HIV testing not collected.
- **$** Cannot infer causality between counseling and testing.
- **$** Cannot evaluate impact of 1998 IOM recommendations (no subsequent data).

Main findings from 1996-1998 PRAMS data

- In 1998, on average, 77% of recently delivered mothers in 11 PRAMS states recalled their prenatal health care provider discussing getting their blood tested for HIV (state range: 68.8%-85.4%).
- In 1998, among 5 PRAMS states with HIV testing information, on average 71.4% of recently delivered mothers recalled being tested for HIV during their prenatal care or at the time of their delivery (state range: 63.9%-79.3%). In addition, among these 5 states, on average 85.8% of mothers who reported being tested recalled a prenatal care provider discussion about getting tested.
- Maternal recollection of a testing discussion increased during the 3-year period in every state, and statistically significant increasing trends in test discussions were observed in 3 of the 7 PRAMS states with 1996-1998 birth data. However, during this 3-year period, no significant changes were observed for prenatal discussions about HIV prevention or maternal HIV testing.
- Despite overall increases in provider testing discussions, differences in maternal recollection by maternal race/ethnicity, source of prenatal care, and Medicaid status persist.

Conclusions

- **$** In 1998, a substantial number of mothers who gave birth received prenatal HIV test counseling.
- **$** In 1998, a high proportion of mothers accepted test counseling.
- **$** Test counseling still remains higher among mothers who are black, Medicaid recipients,

teenaged, or receiving prenatal care from a public provider.

- Between 1996 and 1998, test counseling significantly increased in three states, and testing increased significantly in the two states from which we have data.
- The number of states participating in PRAMS continues to expand. HI, MD, NE, NYC, VT will have data by December of 2001. The next Request for Proposal will be in 2001. The questionnaire is revised every four to five 5 years. States have more options to expand the type of information they collect on prenatal HIV testing and prevention, such as prior testing and reasons for test refusal. The prenatal care questions and HIV testing questions remain.

Emerging Infections Program C Aaron Roome, CT

In Connecticut, we have a STEP-like project on cases exposed from 1995 to now. We have HIV reporting in children by name. We are allowed by communicable disease law to follow up with potential sources of infection, so we use that to look at the mother=s record as well.
On a completely different subject, this is a project that we did as part of the group B Strep demonstration project, which was part of the Emerging Infections Program (EIP) a couple of years ago. We were looking at screening rates for various diseases of perinatal importance for children born in 1996. We found low rates for HIV compared with higher rates for other diseases.

Audit of Prenatal Records, 2000

If you=re interested in the screening rate in pregnant women, this study is being repeated, organized by the Respiratory Diseases Branch of CDC. The primary investigator is Stephanie Schrag (404.639.4820). It=s a national study. Right now GA, TN, MN, CT are participating. They=re going to sample birth records from 1998-99. Vital Records makes the selection. You request the records from the hospitals. A data collection form is already developed. It identifies predictors for who is being tested for all these diseases.

Wrap-up—Mary Lou Lindegren

Key Points

- What should you do with children who are uninfected? DO NOT DELETE this information. Be proactive about going through all the legal steps to maintain the data. To evaluate potential adverse events, we need identifiers. We are currently working with the Council of State and Territorial Epidemiologists (CSTE) to determine an appropriate mechanism and will provide specific guidance in the near future.
- How are we going to evaluate HIV prevention programs using our surveillance data? We're going to need your help in thinking through prevention evaluation, how to know if we're reaching enough women to make a statistically significant comparison. We do know that working with those involved with prevention works better when they ask the questions, rather than when we provide them data we think they need.
- What is our mission? Finding the most complete mother-baby pairs is part of our mission, so part of our efforts have to focus on data sources.
- What is different from HARS? We will collect more data than what is in HARS. And it's not just the data elements; we are going to use more data sources, all four records sources.

The meeting closed with representatives from each state inviting others to contact them and exchange information.

Below is a list to help direct questions.

- States that participated in Enhanced STEP Perinatal Surveillance—MI, LA, TN, SC, NJ, AL.
- States that are funded with no named HIV reporting—CA, PA DC, NY, GA
- States that have UI reporting—MA, IL, MD
- States participating in additional projects—MA, CA, DC, NY, TX